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Delay is inimical to P's welfare: Guidance on clinically-assisted nutrition and hydration for PDoC patients

By Jenny Kitzinger, 15th July 2020

Open Justice Court of Protection Project

<https://openjusticecourtofprotection.org/2021/07/15/delay-is-inimical-to-ps-welfare-guidance-on-clinically-assisted-nutrition-and-hydration-for-pdoc-patients/>

In a recent hearing (Case No. 1375980T, 10th June 2021), Mr Justice Hayden queried why a man had been given continued medical treatment to keep him alive in a prolonged disorder of consciousness (PDoC) for many years – despite evidence from some family members that he would not want this.

It appeared that clinicians had not followed legal and professional guidance about how such decisions should be made.

Whatever the complexities of this case (and I've written about it [here](#)), it was clear that an application to the court (if necessary) should have been made much earlier, probably around 3 years ago, back in 2018. This patient may have been subject to treatment contrary to his best interests for a very long time.

The delay in making a court application was obviously profoundly troubling and frustrating for Mr Justice Hayden, who referred more than once to the professional guidance about clinically-assisted nutrition and hydration (CANH) produced by the British Medical Association and the Royal College of Physicians (published in 2018) and to his own [Guidance about when to refer cases about serious medical treatment to court](#) (published in January 2020).

For me, as someone who often supports families in situations concerning CANH, the depressing thing about the case before Hayden J is not how uniquely delayed the decision-making was, necessitating judicial comment, but rather the reverse: whatever the unique features of this case in particular, the behaviour exhibited by the treating team, which evaded taking responsibility for making best interests decision for their patient, is widespread in many other units across England and Wales.

Mr Justice Hayden's frustration is shared by many others working in this area – and it begs several questions: Has the recent legal and professional guidance helped? If so, how? And if not, why not? And what more can be done to improve best interests decision-making for PDoC patients?

I'm going to address these question by drawing on the work Celia Kitzinger and I have done in the [Coma and Disorders of Consciousness Research Centre](#), which includes formal research interviews with over 100 family members of PDoC patients; delivering [training](#) about law and ethics to healthcare staff; and acting as volunteer advocates in cases where clinicians or families felt outside help was required (which we've written about [here](#)).

My comments are also informed by conversations with healthcare practitioners from 6 different hyperacute, rehabilitation or long-term care centres, who talked with me about what was happening in their own organisations after reading [my earlier blog](#) about this case.

Relevant legal and professional guidance

Clinically-assisted nutrition and hydration (CANH) is a medical treatment. If someone lacks capacity to consent to, or to refuse, such treatment, then decisions about CANH must be made in their best interests (Mental Capacity Act 2005).

The starting point in law is the strong presumption that it is in a patient's best interests to receive life-sustaining treatment, but that presumption can be rebutted if there is clear evidence that a patient would not want CANH provided in the circumstances that have arisen. Up until a few years ago, the legal advice was that withdrawing CANH from PDoC patients required judicial approval. This created several problems: in particular, it led healthcare staff to abdicate responsibility for CANH decisions, and left some families feeling unable to voice their concerns about ongoing treatment ([Kitzinger and Kitzinger 2016](#)). However, in November 2017 there was a key hearing in the High Court about a patient called Mr Y, which was followed by an appeal in the Supreme Court in July 2018. The Supreme Court judgment ([An NHS Trust v Y UKSC 46](#)) was that it is not mandatory to seek judicial approval for decisions to withdraw CANH from PDoC patients.

In the same year, the British Medical Association [BMA] and the Royal College of Physicians [RCP] produced detailed guidance about how to make decisions regarding "[Clinically-assisted nutrition and hydration \(CANH\) and adults who lack the capacity to consent](#)". This guidance (endorsed by the General Medical Council) is complemented by the RCP's (2020) guidance on [Prolonged Disorders of Consciousness](#) which includes detailed information about care, diagnosis and best interests decision-making processes for this patient group.

The legal situation which covers PDoC patients is summarised in Mr Justice Hayden's general guidance on "[Applications relating to medical treatment](#)" (published January 2020). Based upon the decision of the Supreme Court in *Re Y*, this outlines the circumstances in which it is, and is not, necessary to make a court application in relation to providing, withdrawing or withholding serious medical treatment.

6. If the provisions of the Mental Capacity Act 2005 are followed, any relevant professional guidance observed^[2] and relevant guidance in the Code of Practice followed,^[3] including as to the undertaking of the decision-making process, then, if there is agreement at the end of the decision-making process as to:
- the decision-making capacity of; and
 - best interests of the person in question,
- then, in principle, medical treatment may be provided to, withdrawn from or withheld in accordance with the agreement, without application to the court, in reliance upon the defence in section 5.^[4]

If, however, "*at the conclusion of the medical decision-making process*" (para. 8) there is doubt, for example because of a lack of agreement from those with an interest in the person's welfare, and if that lack of agreement relates to the provision of life-sustaining treatment, an application to the Court of Protection must be made. The guidance goes on to state: "*For the avoidance of doubt this specifically includes the withdrawal or withholding of clinically assisted nutrition and hydration*" (para. 9). It presumably is also intended to apply to disagreements about the continuation of CANH (although that is not made explicit).

Where a court application is necessary the importance of bringing such proceedings in a timely manner is underlined by Mr Justice Hayden. Decision makers are advised "*to consider whether steps can be taken to resolve the relevant issues without the need for proceedings*" (para. 14(a)) and to recognise that "*delay will invariably be inimical to P's welfare*" (para. 14(b)). They should make an application to the court in a timely manner if necessary.

How the recent legal and professional guidance has helped

Our research and other work in this area confirms that the *Re Y* judgment and the legal and professional guidance that followed have helped in the following key ways:

- **After *Re Y*, best interests decisions already robustly conducted in the clinical setting could be enacted without further delay.** This was a huge relief for the families involved:

as one wife of a PDoC patient said, it felt as if her husband's best interests were really being put first (see a filmed extract from her interview [here](#)).

- **New discussions were started as families felt more able to speak up about what they thought the patient would have wanted.** After the *Re Y* judgment, we experienced a sudden increase in approaches from family members of patients who had been in PDoC for years or decades. These people were explicit that not having to go to court meant they now finally felt able to challenge ongoing CANH. This included, for example, the family of a woman who had been in a permanent vegetative state for over 33 years.
- **Clinicians were more likely to initiate discussion of CANH.** One healthcare professional, for example, told me she had (prior to 2018) discharged dozens of patients in permanent vegetative states into care homes, without ever raising the question of whether or not CANH was in their best interests. (“*They’re the ones*”, she said, “*that keep me awake at night*”). The change in legal and professional guidance, however, means that she and her colleagues now routinely discuss CANH as a best interests decision in relation to all new patients now coming through their centre: “*The Y case changed our whole approach. Being able to come to a clinical and family consensus without going to court seems ‘do-able, whereas before the idea of going to court was stressful.*” [Allied Healthcare Professional, specialist rehab centre]
- **Guidance about the best interests decision-making process helped healthcare professionals at a very practical level.** The detail of the BMA/RCP guidance on CANH (combined with the RCP guidance around PDoC) is seen as invaluable. The comprehensive quality of information, combined with user-friendly formats (boxes highlighting key legal points, flowcharts and checklists) have helped staff to navigate the whole process of talking with families and obtaining the right clinical information and second opinions “*I would literally carry the guidelines in my hand to all key meetings with loads of post-it notes.*” [Clinical Lead, specialist long term care centre]
- **Specific parts of the guidance also help with documentation and auditing.** The [BMA/RCP proforma](#) for documenting decisions about CANH was highlighted as particularly valuable because:

“Not only does it guide you through the process and make sure you’ve thought about everything but it answers my Trust’s question: how do we know when we’ve done this correctly?’ We send the proforma to the Trust Governance Department who then assess whether the process has been done with all due diligence, and decisions can be audited. [This also means that] if it needs to go to court, all the information is there about the process that’s been followed and it highlights any areas of disagreement that the court needs to address.” [Consultant in a specialist PDoC assessment unit]

The new legal and professional guidance means that many cases are now resolved in discussion between clinicians and patients’ families without the need for court. This is happening both in centres where robust best interests processes were already established, and in centres where this is developing as a new skill set (since previously they had provided CANH by default).

Healthcare professionals engaging with the guidance say that, even if they were hesitant at first, they are gaining confidence with experience and feel very positive about improvements in patient-centred care and in increased reflective practice across the entire multi-disciplinary team.

Patients’ best interests seem well-served, insofar as the documentation we’ve seen suggests that decision-making where withdrawal of CANH is considered is detailed and thorough. The process followed meets, or sometimes exceeds, what a court might have required. For example, formal

diagnostic evaluation designed to detect even minimal consciousness (a “SMART”) was commissioned for a woman who’d been in PVS for over three decades – something which might not have been considered necessary by a court given the length of time since her original injury, the lack of responses observed by family and staff, and the fact that, according to testimonies from her family, some minimal consciousness would make no difference to what she would have wanted – indeed if she were minimally conscious this would be worse for her.

By contrast, we note that some documentation we’ve seen about decisions to continue CANH shows that these decisions are often not robust and display a lack of awareness of the BMA/RCP guidance, or even the Mental Capacity Act 2005. We have seen records of so-called ‘best interests’ decisions to fit feeding tubes, or to continue with CANH, which indicate that treatment is in the patient’s best interests simply on the grounds (for example) that: “Patient cannot swallow” or “Wife consents”.

Alongside the need to monitor the impact of the new guidance, we therefore want to underline the importance of a register for PDoC patients and proper audit of their care and of best interests decision-making (in relation both to discontinuing and to continuing life-sustaining treatment).

Difficulties with, and resistance to, following the guidance

Compliance with the relevant legal and professional guidance is neither uniform nor comprehensive and the issue of treating patients by default continues to be a problem. Healthcare professionals seeking to follow the guidance sometimes describe challenges such as lack of training or resources to permit proper best interests reviews of CANH, so the ‘easiest’ thing to do is not to address the issue at all. They may also be discouraged by a lack of clear commitment from their organisation, or even an implicit sense that there is somehow a contradiction between a professional commitment to rehabilitation, on the one hand, and a commitment to best interests, on the other. Others find their own sense of identity threatened or they worry that even raising a question about CANH might undermine their relationships with families.

One consultant, just starting a conversation with a family about whether providing CANH to their relative was appropriate any more, described how difficult this was for her in the following terms: *“It’s hard to be gamekeeper turned poacher. I feel an internal dichotomy, even though my guiding light is to do the right thing by the individual”*.

It can be tempting to wait for the family to raise the issue, or to let years go by in the hope that, eventually, everyone will be *“on the same page”*, or even that the patient will have moved on to a different setting, so the problem can be passed on to someone else.

Some healthcare professionals have told me that they explicitly limit their compliance with the professional guidance. For example, they won’t raise CANH as a best interests decision until at least two years after injury, or simply can’t bring themselves to discuss the issue with any family whose relative has been maintained in PDoC for an extensive period. There is also an uneven spread of skills in decision-making. Some GPs, for example, feel that they have neither the time nor the skill to do anything other than continue to prescribe CANH for all patients in the care homes they serve. Most importantly, perhaps, there seems to be a huge level of **inertia built into the system**. Years of delay sometimes occur because:

- No particular healthcare professional **feels responsible for decisions** to (dis)continue CANH
- Assessing best interests re ongoing CANH is **not seen as urgent** so little priority is given to setting up the necessary meetings and second opinion

- The legal presumption in favour of life is interpreted as if this presumption can be used to treat indefinitely, **regardless of clear evidence that a patient would not want CANH** in their current circumstances

and/or

- the **decision to continue with CANH** is seen as “**not making a decision**” at all. And the act of continuing (e.g. to sign off on repeat prescriptions of formula or routine replacement of old or damaged feeding tubes) is seen as “**no action**”. This allows some individuals to position themselves as simply “not getting involved” when in fact they are actively involved in continuing CANH.

The way in which continuing CANH is conceptualised is a key problem, with some clinicians or managers not getting to grips with the vital principle that “*the fundamental question is whether it is lawful to give the treatment, not whether it is lawful to withhold it*” (Para 20 Aintree <https://www.supremecourt.uk/cases/docs/uksc-2013-0134-judgment.pdf>)

Outright opposition to the guidance also exists in some quarters. This includes:

- **institutional or management opposition.** For example, I was informed by one senior figure that he routinely removes ceilings of treatment for all patients coming into his unit because “*we’re a rehab centre not a knacker’s yard*”. In such circumstances, individual healthcare professionals can find it very difficult to follow professional guidance. A GP trying to discuss CANH as a best interests decision was “*aggressively challenged*” by the care home manager. Other healthcare professionals ran into difficulties with managers who were “*hostile*” or concerned about a perceived “*reputational risk*” to the organisation. Another healthcare professional told me the religious ethos of his organisation means he has had to be cautious and strategic in bringing the organisation into line with the guidance, although he has now succeeded and is extremely passionate about how genuine religious compassion was being shown to patients in ways that now fully comply with legal and professional guidance.
- **resistance from some senior clinicians.** Some allied healthcare professionals who’ve trained with us subsequently report that there is a limit to what they can actually do with their new knowledge of the legal and professional guidance because they are working with consultants who are implacably opposed to CANH-withdrawal. We’ve some direct experienced of this ourselves when we’ve been in meetings where doctors have informed families that withdrawing CANH is equivalent to euthanasia, is bound to lead to a painful death, and/or that they don’t agree with the law and have no intention of following it. Many evoke a medico-ethical position they see as being ‘above’ the law, or a personal morality which means they feel compelled to resist professional guidance.

For any of these reasons, and sometimes a combination of several, patients’ best interests can be ignored, and therefore overridden. This means that families desperate to end what they’ve come to see as a violation of their relative’s dignity are routinely faced with excruciating delays and feel compelled to “lobby” for withdrawal, leaving them feeling implicated in the death of their loved one. Our interviews display this vividly, e.g. [here](#), where one person describes the difficulty of getting healthcare professionals to take responsibility for decisions, and [here](#) and [here](#) where another describes her experiences and says she wishes the possibility of withdrawing CANH had been raised proactively much earlier.

A case study outside the courts

Although there have been many positive changes, we are still encountering cases of lengthy delay inimical to patient welfare. Many of these cases never come before a judge – and, indeed, we do our best to support robust and timely resolution without involving the courts. What cases we've worked on demonstrate is continuing failures in best interests decision-making on the ground. For example, we were asked to help support decision-making for Chris, a man in his 40s, whose wife struggled to get those caring for him to consider his best interests in relation to CANH over several years: her experience is outlined in the case study box below.

Case study: Chris

Yvonne's husband, Chris, had a cardiac arrest in March 2016. His brain was left without oxygen for a long time. At first, she believed he might recover in spite of "pessimistic" predictions from his clinical team. However, her view had shifted by 9 months after his injury:

"I remember the first Christmas, unwrapping his presents for him and just feeling 'this is wrong... You go into this weird world [in the care home] ... I just kept feeling 'Chris wouldn't want this'. But in there it is the norm and they don't hear anything else."

Nobody raised the question of CANH with her, but after the *Re Y* case, she tried to initiate discussion herself:

"It was after all the publicity about the Y court case. I asked for a conversation with the nursing manager and he replied: 'What do you think we're going to do. Go around killing all our patients?' and toddled off down the corridor... Medical staff that were looking after Chris didn't want to have that conversation with me. They cut me dead on it."

Yvonne eventually persuaded her husband's GP to hold a best interests meeting about CANH. It took him 4 months to arrange that meeting, but when it finally happened, everyone agreed (says Yvonne) that withdrawing CANH was the right thing to do.

However, in late October 2019, the GP emailed Yvonne saying that he'd been given legal advice that he should seek "the comfort" of a court order and (incorrectly) telling her that she needed to take the case to court. It was this that prompted Yvonne to contact us:

"Surely if the doctors believe that they are not acting in in his best interests [by continuing CANH] and they want the comfort of the court order, then it is their duty to do this for my husband ... It's been extremely troubling for me to chase doctors literally begging them to stop feeding my husband. It's a terrible situation to find myself in and I've had so many closed doors to try and prise open."
(Email, 4 November 2019)

We made repeated attempts to get the GP to follow legal and professional guidance but, after several weeks, the GP, along with all the colleagues in his practice, belatedly declared conscientious objection to CANH withdrawal. This supposed conscientious objection came completely out of the blue and was not declared until December 2019 - several months after what Yvonne now refers to as "the Fake Best Interests Meeting" chaired by the GP. At that point we supported Yvonne to move her husband to a different centre.

Yvonne's husband was admitted to a specialist unit on 12 February 2020. Testing and clinical diagnosis confirmed that he was in a Permanent Vegetative State. A meeting was held with the family on 28 February 2020, and a second opinion subsequently confirmed both the diagnosis and the best interests decision. CANH was withdrawn on 13 March 2020. Chris died on 26 March 2020 – over three years from the date his wife considered the treatment provided not to be in his best interests, and 18 months after she'd tried to raise this with staff following the *Re Y* publicity.

Yvonne is extremely grateful to the specialist unit that was able to properly and speedily review her husband's best interests, and to act within weeks. She is worried, however, for patients like Chris who remain in the care home that treated him with such disregard for him as a person. She's also concerned that residents in that care home have access only to a single GP practice – one which has declared (at least to us) a collective 'conscientious objection' to best interests decision-making about CANH.

So, what can be done to improve best interests decision-making about CANH?

There have clearly been huge improvements, and there is equally clearly still a huge amount to be done to roll out good practice and to ensure that all PDoC patients receive high-quality, patient-centered care, compliant with legal and professional guidance.

We've outlined many recommendations in [earlier publications](#), but here I want to highlight the importance of the professional guidance and of the BMA/RCP proforma – use of which supports detailed and proportionate documentation of decisions. It is also important that no one is simply 'warehoused' indefinitely in a care home, without access to specialist input: this is most likely to happen to patients judged to have 'no rehab potential' – the very patients who perhaps most need specialist input in relation to best interests review. There may also be a role for the Care Quality Commission to inspect levels of compliance with best interests guidance. Reluctantly, we've come to the view that some referrals to the General Medical Council may be the only way of getting some actively-resistant doctors to take note of their obligations.

The Court of Protection only ever sees a minority of cases where best interests decisions need to be made. But the court plays a crucial role in exploring, defining and setting standards for best interests decision-making beyond the courtroom – in the clinic and in the community. Alongside challenging delays in bringing cases to court, the Court of Protection can make it crystal clear via its judgments and judicial guidance that:

- continuing CANH (as well as withdrawing it) is a decision and constitutes 'action'
- best interests assessments need to be undertaken in order to justify continuing CANH as much as to justify withdrawing it.
- all such decisions and actions must be robustly evaluated and documented in the best interests of the patient.

In training healthcare professionals, we've found that words matter – and that this reorientation towards thinking about justification for giving treatment (as well as for withholding or withdrawing it) can be revelatory, thought-provoking and mobilise a different approach to the issue.

The Court of Protection is also uniquely positioned to promote stakeholder engagement with recent legal and professional guidance. The court can take the opportunity of underlining (a) that CCGs who commission treatment, including CANH, must show that it is in the best interests of the person concerned; and (b) that no organisation (whether a private hospital, NHS rehabilitation centre, or charity-run care home) can simply 'opt out' of the relevant legal and professional guidance. The BMA/RCP Guidance puts it like this (p.33)

Provider organisations, including care homes, that carry religious or other convictions that would prevent them from making and implementing particular decisions about CANH should be open about that fact when a best interests decision is needed. All such organisations have a duty, however, to comply with the law, including ensuring that best interests assessments are carried out on a regular basis. These assessments should specifically consider the question of whether CANH continues to be in the patient's best interests as part of the care plan review. Where necessary, organisations should make arrangements for these assessments to be carried out in, or by staff from, another establishment.

Finally, it needs to be emphasised that individual healthcare professionals cannot simply 'follow their conscience' where that means imposing their values on vulnerable patients. Doctors may

not offer a treatment because they don't consider it clinically appropriate – but they should not, simply based on their own values, either deny the patient an available treatment they would have wanted, or impose a treatment he or she would have wished to refuse. Approaching each patient as an individual is core to good practice.

Given the persistence of poor practice, and active resistance from some quarters, the court could also make clear that continued provision of medical treatment when it is not in someone's best interests is an assault, and that clinicians will not be able to rely on the defence in s.5 of the Mental Capacity Act 2005 – meaning that there is a risk to them and to their organisations of claims for damages.

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